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ABSTRACT

In July, 1983, the Center for Independent Living of Greater Bridgeport and its cooperating agencies conducted a survey of 32 people, the majority of whom were developmentally disabled and resided in institutional or community settings, in both rural and urban areas. This report addresses the perceived needs and levels of independence experienced by these two distinct populations as a result of a follow-up study conducted in July, 1984. The questionnaire used in 1983 was revised to focus upon services used and levels of consumer satisfaction. Areas addressed were demographics, education, employment and training, income and benefits, housing, recreation and leisure time, transportation, medical treatment, counseling, advocacy, and legal issues. The objective of the study was to determine the level of consumer use of and satisfaction with community-based services, use of and satisfaction with independent living services, and what, if any, differences exist between those in institutionalized and non-institutionalized groups regarding perceived needs, levels of independence, and satisfaction with available resources. Although the sample size was too small to yield definitive results overall, the findings indicated that people living in the community reported greater satisfaction and better use of both generic and categorical services. When services were not used, reasons given included lack of transportation, prohibitive cost, or lack of interest. (Author/KC)

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CENTER FOR INDEPENDENT LIVING OF GREATER BRIDGEPORT

COMPUTERIZED COORDINATED SERVICE CENTER

SURVEY UPDATE: THE PERCEIVED NEEDS AND LEVEL OF INDEPENDENCE OF INSTITUTIONALIZED VERSUS NON-INSTITUTIONALIZED DEVELOPMENTALLY DISABLED PERSONS

DECEMBER, 1984

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CE 041 475

Perceived Needs Report - 1984

ABSTRACT

In July 1983, the Center for Independent Living of Greater Bridgeport and its cooperating agencies conducted a survey of 32 people, the majority of whom were developmentally disabled and resided in (a) institutional or (b) community settings, in both rural and urban areas.

This report addresses the perceived needs and levels of independence experienced by these two distinct populations as a result of a follow-up study conducted in July 1984. The questionnaire used in 1983 was revised and focused upon services utilized and levels of consumer satisfaction. Areas addressed were demographics, education, employment and training, income and benefits, housing, recreation and leisure time, transportation, medical treatment, counseling, advocacy, and legal issues.

The objective of this study was to determine the level of consumer utilization of and satisfaction with community-based services, utilization of and satisfaction with Independent Living Skills, and what, if any differences exist between those in institutionalized and non-institutionalized groups regarding perceived needs, levels of independence, and satisfaction with available resources.

Overall, the findings indicated that people living in the community reported greater satisfaction and better utilization of both generic and categorical services.

PERCEIVED NEEDS REPORT

INTRODUCTION

In October 1982, the Center for Independent Living of Greater Bridgeport (CILGB), in cooperation with Bridgeport's Office of Handicapped Services (OHS) and the Western Connecticut Association for the Handicapped and Retarded (WeCAHR), received a Developmental Disabilities Grant of National Significance from the U.S. Department of Health and Human Services (HHS). As part of this project CILGB established the Computerized Coordinated Service Center (CCSC). CCSC (a) expands services in targeted urban and rural areas, (b) utilizes advanced technology, (c) surveys generic and categorical services available to people with disabilities, and (d) conducts studies and reports on major findings, with implications of interest to those involved with the quality of life of persons with disabilities. In July 1984, CILGB conducted a follow-up on a similar survey accomplished in 1983, which focused upon persons with disabilities, their families, and professionals. This report summarizes the results of the 1984 survey. (The results of the 1983 survey are available from CILGB.)

This report addresses the perceived needs, level of utilization of and satisfaction with community services, level of satisfaction with Independent Living (IL) services, and what increase, if any, occurred in consumer utilization of community resources as a result of involvement with IL services over the past year. The survey was conducted in two targeted communities, one urban and one rural. The city of Bridgeport and its surrounding towns comprised the urban area. The city of Danbury and its surroundings towns represented the rural (sub-urban) sector. The principal aim of the study was to determine (a) whether or not levels of utilization and satisfaction with services had increased as a result of IL services, and (b) consumers' opinions of IL services.

This report will address several important aspects involved in the survey including (a) the methodology utilized, (b) the results of the consumer surveys, (c) the results of the surveys involving Skilled Care Facility (SCF) and Intermediate Care Facility (ICF) professional staff members, (d) a summary, and (e) conclusions addressing the perceived needs of persons with developmental disabilities.

Methodology

Two consumer groups were surveyed. Group A included people who were living in an institutional setting, i.e. SCF's or ICF's, including nursing homes and group homes. Group B consisted of individuals residing in a non-institutionalized, independent living situation, including people living at

home, in a group living facility, or in a transitional living program. The majority of the individuals surveyed were developmentally disabled and had previously or were currently receiving CILGB services. Confidentiality was guaranteed to all participants.

Selection of survey participants was based upon (a) willingness to participate in the survey, (b) comprehension of survey material, (c) participation in CILGB services, and (d) identification as being an individual with a developmental disability.

A modified survey was distributed to SCF and ICF staff to gather information on their perception of residents' needs and quality of life.

Instrument Development

A questionnaire-type format was selected as the instrument for the consumer satisfaction survey. Participants were offered a limited number of response options, with some opportunity for discussion or elaboration available (See Appendix A).

The SCF and ICF staff survey contained both closed and open-ended questions. This questionnaire allowed for professional input and discussion regarding the needs of residents and the staff's perception of their ability to utilize community services (see Appendix B).

Design of Survey

The survey was developed by focusing on areas and elements that generally affect an individual's quality of life. The questionnaire was designed to gain information on individuals' present lifestyles, services they have utilized, and the level of satisfaction they have experienced with these services. The specific areas addressed were demographics, education, employment and training, income and benefits, housing, transportation, and recreation and leisure time, as well as medical, counseling, advocacy, and legal issues. A section addressing utilization of and satisfaction with CILGB services was also included. The desired outcome of the survey was that the information gathered would convey the actual level of independence perceived and experienced by the participating individuals; significant differences between the two groups were expected.

The initial draft of the survey was formulated by the CILGB Information and Resource Specialist and was a modified version of the questionnaire developed for the July 1983 survey. After consulting with the Program Director and CILGB case management staff, a final format was formulated and prepared for distribution.

Data Gathering

Prior to implementing the survey, the Information and Resource Specialist, Program Director, and CILGB case management staff met to review the final draft and clarify specific questions involved in the survey. An in-person, one-to-one interview technique was chosen as the method for conducting the survey. The survey was conducted over a two week period.

Staff members from several SCF's were contacted and asked to participate in the survey. Of the twenty-four originally contacted, six responded to the survey - three from the urban area, three from the rural area.

Response Rates

For Group A the initial goal was to interview 10 developmentally disabled SCF and ICF residents. Eventually 5 were interviewed. All had received services from CILGB. Two respondents were from the rural area and three were from the urban area.

For Group B the initial goal had also been set at 10 individuals. This was achieved. All those interviewed were consumers. Three were from the rural area and six were from the urban area.

The response rate for the staff survey resulted in six completed questionnaires.

Data Analysis

Because of the small total number of consumer satisfaction surveys undertaken and completed, the Information and Resource Specialist recorded responses manually.

FINDINGS

Demographics

The total sample consisted of fifteen participants. Of these, only 5 resided in SCF or ICF facilities; the remaining 10 were residents of a non-institutionalized, community setting. Table 1 gives a demographic breakdown of participants.

TABLE 1

AREA	GROUP A		GROUP B	
	No.	%	No.	%
Urban	4	80	5	50
Rural	1	20	5	50

Total	5	100	10	100

GENDER	GROUP A No.	%	GROUP B No.	%
Male	3	60	5	50
Female	2	40	5	50
Total	5	100	10	100

Age Distribution

No distinct pattern of age distribution was clearly discernible. However, the majority of those responding to the survey (66%) were between the ages of 21 and 50. Table 2 shows the age distribution.

TABLE 2

AGE	GROUP A No.	%	GROUP B No.	%
Under 21	0	0	3	30
21 - 30	0	0	1	10
31 - 40	2	50	3	30
41 - 50	1	25	3	30
51 - 60	1	25	0	0
61 - 70	0	0	0	0
71 +	0	0	0	0
Total	4*	100	10	100

*One individual in Group A did not respond to this survey question.

Disability

Participants were asked to indicate the nature of their primary disability. Table 3 represents the respondents' answers within their respective groups.

TABLE 3

DISABILITY	GROUP A No.	%	GROUP B No.	%
Mental Retardation	0	0	4	40
Physical	5	100	2	20
Mental Disability	0	0	1	10
Visual Disability	0	0	0	0

Hearing Impairment	0	0	0	0
Learning Disability	0	0	0	0
Multiple	0	0	1	10
Other (TBI, seizure disorder)	0	0	2	20
Total	5	100	10	100

Physical Disabilities

Individuals with a physical disability were asked to indicate their specific disability so that the group surveyed would be more accurately described and to identify those with developmental disabilities. Table 4 illustrates the types of physical disabilities.

TABLE 4

DISABILITY	GROUP A No.	%	GROUP B No.	%
Multiple Sclerosis	0	0	1	50
Rheumatoid Arthritis	0	0	1	50
Cerebral Palsy	2	40	0	0
Amputee	1	20	0	0
Paraplegia	1	20	0	0
Right Hemiplegia	1	20	0	0
Total	5	100	2	100

Age at Onset of Disability

Many of the respondents were disabled from birth. Table 5 illustrates this data.

TABLE 5

AGE	GROUP A No.	%	GROUP B No.	%
Birth	2	40	4	40
Under 22	0	0	3	30
Over 22	1	20	1	10
No Response	2	40	2	20
Total	5	100	10	100

Independent Living Services

Tables 6 through 9 provide a breakdown of the number of months/years respondents have been involved in Independent Living (IL) services, their overall satisfaction with those services, any noted changes in their lives as a result of IL services, and any change in their utilization of community services as a result of IL services.

TABLE 6

Involvement in IL Services

LENGTH OF TIME	GROUP A		GROUP B	
	No.	%	No.	%
0 - 6 Months	2	40	0	0
6 mo. - 1 yr.	0	0	4	40
1 - 2 yrs.	3	60	4	40
over 2 yrs.	0	0	2	20
Total	5	100	10	100

TABLE 7

Satisfaction with IL Services

OVERALL SATISFACTION	GROUP A		GROUP B	
	No.	%	No.	%
Very Satisfied	2	40	4	40
Satisfied	3	60	5	50
No Effect	0	0	0	0
Dissatisfied	0	0	1	10
Very Dissatisfied	0	0	0	0
Total	5	100	10	100

TABLE 8

Life Changes

CHANGES IN LIFE	GROUP A		GROUP B	
	No.	%	No.	%
Yes	4	80	9	100
No	1	20	0	0
Total	5	100	9	100*

*One person did not respond.

TABLE 9

Community Services

UTILIZATION OF OTHER SERVICES	GROUP A No.	%	GROUP B No.	%
Increased Utilization	4	80	6	60
No Change	1	20	4	40
Total	5	100	10	100

The remainder of the survey dealt with (1) services respondants utilized during the past year and how they rated their ability to utilize these services once they had participated in Independent Living Services, and (2) respondents' levels of satisfaction with the various services proviced by CILGB. Each of these areas will be discussed separately.

Employment and Training

Table 10 shows the level of satisfaction with Employment and Training services for Group B, (none of those from Group A utilized these services).

TABLE 10

EMPLOYMENT/TRAINING	GROUP B No.	%
Very Satisfied	0	0
Satisfied	2	20
Dissatisfied	1	10
Very Dissatisfied	0	0
Not Applicable	7	70
Total	10	100

Of those who utilized these services, 67% said they were satisfied with the services provided through CILGB. No one expressed dissatisfaction with CILGB.

Division of Vocational Rehabilitation

Only one person from Group A utilized DVR services. This individual was satisfied with DVR services received. This person also expressed satisfaction with CILGB in this area. Group B is described in Table 11.

TABLE 11

DVR	GROUP B No.	%
Very Satisfied	2	20
Satisfied	3	30
Dissatisfied	1	10
Very Dissatisfied	0	0
Not Applicable	4	40
Total	10	100

All of those who utilized DVR services reported satisfaction with CILGB.

Income and Benefits

All of those from Group A and B who received assistance in this area from CILGB expressed satisfaction. Table 12 shows reported level of satisfaction with services, providing financial benefits, such as Disability, SSDI, SSI, DHR, and the Veterans' Administration.

TABLE 12

INCOME/BENEFITS	GROUP A No.	%	GROUP B No.	%
Very Satisfied	1	20	1	10
Satisfied	1	20	3	30
Dissatisfied	0	0	1	10
Very Dissatisfied	0	0	1	10
Not Applicable	3	60	4	40
Total	5	100	10	100

Housing

This area included skilled care facilities, group homes, intermediate care facilities, and independent living situations. Twenty percent of Group A respondents and 80 percent of Group B did not respond to this question. The information shown in Table 13 reflects only those who responded. All respondents were satisfied with CILGB's assistance in this area.

TABLE 13

HOUSING	GROUP A No.	%	GROUP B No.	%
Very Satisfied	1	25		0
Satisfied	2	50	1	50
Dissatisfied	1	25	1	50

Very Dissatisfied		0		0
Not Applicable				
Total	4	100	2	100

Recreation and Leisure Activities

All but one individual who responded to this question expressed satisfaction with CILGB. One person stated that she resides in Danbury and can not get to Bridgeport to participate in CILGB recreational programs. Table 14 describes the results.

TABLE 14

RECREATION/LEISURE	GROUP A		GROUP B	
	No.	%	No.	%
Very Satisfied	2	40	4	40
Satisfied	2	40	2	20
Dissatisfied	0	0	1	10
Very Dissatisfied	0	0	0	0
No response	1	20	3	30
Total	5	100	10	100

Transportation

Those people who utilized CILGB's transportation expressed a high level of satisfaction. Other transportation utilized included the Human Services Transportation Consortium, private vans, and buses. Table 15 shows the responses.

TABLE 15

TRANSPORTATION	GROUP A		GROUP B	
	No.	%	No.	%
Very Satisfied	1	20	2	20
Satisfied	2	40	3	30
Dissatisfied		0		0
Very Dissatisfied		0		0
No Response	2	40	5	50
Total	5	100	10	100

Medical

Comparable numbers of groups A and Group B expressed satisfaction with the medical services they received. All who responded were satisfied with CILGB's assistance in this area. More then two-thirds of each group did not respond. Table 16 shows the results.

TABLE 16

MEDICAL	GROUP A No.	%	GROUP B No.	%
Very Satisfied	1	20	2	20
Satisfied	1	20	1	10
Dissatisfied		0		0
Very Dissatisfied		0		0
Not Applicable	3	60	7	70
Total	5	100	10	100

Counselling

This area included individual, group, and family counseling programs, as well as Independent Living counseling. All who participated in counselling expressed satisfaction with CILGB. Table 17 shows the results.

TABLE 17

COUNSELING	GROUP A No.	%	GROUP B No.	%
Very Satisfied	3	60	4	40
Satisfied	2	40	3	30
Dissatisfied	0	0	0	0
Very Dissatisfied	0	0	0	0
Not Applicable	0	0	3	30
Total	5	100	10	100

Advocacy and Legal Issues

Table 18 shows consumer satisfaction with services in this area. All from Group A and Group B who had been involved with advocacy services with CILGB were satisfied.

TABLE 18

ADVOCACY	GROUP A No.	%	GROUP B No.	%
Very Satisfied	1	20	1	10
Satisfied	1	20	3	30
Dissatisfied	0	0	1	10
Very Dissatisfied	0	0	0	0
Not Applicable	3	60	5	50
Total	5	100	10	100

Education

No one from Group A and the majority from Group B had been involved with educational services in the past year. Ten percent of Group B expressed satisfaction with those services, and 10 percent were dissatisfied. All those from Group B who responded were satisfied with CILGB involvement.

The last section of the questionnaire discussed CILGB's specific services and consumer satisfaction with these services. Table 19 shows the results.

TABLE 19

Satisfaction with CILGB Services

SERVICE	VERY SAT. % GROUP		SATIS. % GROUP		DISSAT. % GROUP		VERY DIS. % GROUP	
	A	B	A	B	A	B	A	B
IL Counseling	40	50	60	10	0	0	0	0
IL Skills	20	50	40	10	0	0	0	0
Occupational Therapy	0	30	20	0	0	0	0	0
Activities of Daily Living	0	30	20	10	0	0	0	0
Housing Assistance	40	0	60	20	0	0	0	0
Transitional Living	20	0	20	10	0	0	0	0
Personal Advocacy	20	40	60	40	0	0	0	0
Benefits Counseling	20	40	40	20	0	0	0	0
Follow-up	0	10	0	20	0	0	0	0
Special Interest Classes	0	20	0	10	0	0	0	0
Peer Counseling	0	20	20	0	0	0	0	0
Consumer Action	0	0	0	10	0	0	0	0
Volunteer Program	0	0	0	0	0	0	0	0
Cultural/Recreation	20	40	40	20	0	0	0	0
Support Group	40	10	40	10	0	0	0	0
Outreach	40	50	20	0	0	0	0	0
Information/Referral	40	40	40	20	0	0	0	0
PCA Referral	0	20	40	0	0	0	0	0

*Percentages reflective of total responding in each group.

CONCLUSION

The purpose of this paper was to address the perceived needs of persons with disabilities, their level of utilization and satisfaction with community services, their level of satisfaction with Independent Living Services, and the extent of any increase in Consumer utilization of community rescurces as a result of involvement with IL services. Since the total population surveyed was small, the results are not meant to be conclusive of all persons with disabilities.

In general, those surveyed were satisfied with the Independent Living services they received. They noted some changes in their lives as a result of those services and found that they were able to better utilize other community services.

Community-based participants expressed levels of dissatisfaction with services in employment/training, vocational rehabilitation, income/benefits, housing, recreation/leisure, and advocacy/legal issues. People residing in institutions expressed some dissatisfaction with housing services. A larger percentage of the community-based individuals were dissatisfied with their housing arrangements.

Other major differences were apparent in employment/training and vocational rehabilitation services. No one from Group A utilized employment/training services and only one person used Division of Vocational Rehabilitation services. Thirty percent of Group B were involved with employment/training and 60 percent with DVR.

The overall results of this survey indicated that community-based persons with disabilities have greater access to more services than individuals who reside in an institutional setting. Hence, they utilize such services to a greater extent. The results tend to support the conclusions of the consumer survey report issued in 1983 that community living with adequate support systems appear to be a more productive and viable way of life for people with disabilities.

STAFF SURVEY

The staff survey was designed to elicit from staff members at Skilled Care or Intermediate Care facilities input regarding their perceptions of the needs of developmentally disabled residents of their facilities who have the potential of utilizing community services. The questionnaire used included categories similar to the consumer satisfaction questionnaire. Voluntary staff participants were asked their opinions of (a) residents' utilization of services in the community and in the facility, (b) residents' needs and (c) what might prevent the residents from meeting their needs. Six individuals responded to this survey. The results are as follows:

The respondents were people in supervisory and/or administrative positions. The percentage of time spent in direct patient contact varied from 30% to 100%.

The primary developmental disabilities of residents were reported to be cerebral palsy and/or mental retardation. The majority of developmentally disabled residents had attained a high school education.

In the area of income and benefits, staff stated that they help residents with application for these services, but do not spend a great deal of time with this area. Five of the staff interviewed stated that they had assisted residents with appealing a decision in regard to benefits. Four staff indicated that the amount of income residents had available allowed them money for entertainment, luxury items, etc.

Four staff members stated that they felt developmentally disabled residents in their facilities could live in more independent living situations, if these were available. They indicated that services such as funding, assistance in locating housing, independent living skills instruction, activities of daily living instruction, personal care assistance, transportation, job training, employment, and transitional living programs would assist the residents in achieving more independent living situations.

The staff were also questioned about service utilization, types of services needed, and what prevented residents from utilizing available services. All respondents stated that transportation services were used and that expanded transportation services were needed for evenings, weekends, holidays, and leisure activities. Lack of availability, cost, and limited hours of operation were cited as reasons for residents' failure to utilize other services or community resources.

Four respondents stated that counseling services were utilized. Residents addressed such issues as coping with a

disability and personal issues. Under-utilization of this type of service was said to be due to a lack of staff available to provide the service.

Three respondents said that residents utilized advocacy services. These services were used for conservatorship and placement problems.

Regarding education, three respondents stated that residents utilized services offered at such area agencies as the Kennedy Center, as well as those offered through Adult Basic Education classes. Classes in sign language and daily living skills were identified as being needed or wanted by residents. Cost of classes, lack of transportation, and lack of interest were identified as reasons why classes were under-utilized.

Two respondents stated that residents used community medical services for such things as blood pressure screening and immunization. Since many of the services offered in the community are also offered in the SCF, they are not utilized frequently by residents.

Five respondents stated that residents use recreational programs and that more diversified recreational activities and group socialization events are needed. Lack of interest, cost and unavailability of transportation, and a feeling that many of the programs offered are geared toward persons who are elderly were identified as reasons why residents do not utilize offered programs.

Due to the small sample it is not possible to draw any major conclusions, but it is possible to compare the results from 1983 with those of 1984. In both instances, respondents indicated that they assisted residents with benefits and income appeals when appropriate, but did not spend a large proportion of their time in that area. Two-thirds of the staff surveyed in 1984 felt that the income available to residents allowed them money for entertainment, as compared to only one third of the staff surveyed in 1983.

Two-thirds of both groups felt that residents could live more independently, if appropriate situations were available. They identified similar types of services necessary for this.

In the area of counseling, both groups identified coping with disabilities as an issue residents would want to address. Both groups stated that lack of staff at their facilities and in community was a major problem in providing this service to residents.

As in 1983, residents utilized a variety of advocacy services. Lack of the transportation necessary to use these services was identified as a problem.

There were also similarities responses regarding educational services. Under-utilization of these services was said to be reflective of the costliness of classes and the lack of transportation.

In both years, community medical services were infrequently used because many of them were also offered at the facility.

In the area of recreation and leisure, similarities were again noted. These included expense, lack of transportation, lack of interest, and insufficient staff to accompany the groups.

One of the most frequently cited problems in both the 1983 and 1984 surveys was the lack of or the expense of transportation for residents.